

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

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African American , Lower Education

Portland, OR

Moderator: Barbara K. Hairston

SECTION I: GENERAL IMMUNIZATIONS AND HEALTH CARE

There were 8 respondents, 4 male and 4 female. They cited a variety of ways that they take care of themselves which included family interaction, physical activity, and spirituality.

I. Prevention

Respondents were concerned with childhood, chronic and infectious diseases, as listed below.

- Hepatitis
- Sick cell
- Measles
- Mumps
- Multiple sclerosis
- Chicken pox

II. Immunizations

A. *Reasons not to get vaccinated*

- This group was pro-immunization but could identify a number of reasons why they believed others did not immunize their child. By category these included fear of hurting the child, lack of knowledge, and low priority.

My sister in law didn't, and she said that she just felt that was putting her child through a lot of pain.

Some people just don't take the time.

B. *Reasons to get vaccinated*

- The primary reasons cited for vaccinating children were protection, complying with the norm, and fulfilling their responsibility for keeping their children safe and healthy.

Protect their kids.

Help keep them safe and healthy.

Just follows into the norm.

C. Ways parents are reminded of vaccine schedule

- This group seemed somewhat involved with record keeping. Several had immunization charts which they had been filling out since the time of their child's birth. They used these to record and schedule immunizations. Those who did not keep records relied on the pediatrician to alert them that it was time for an immunization.

From the time of birth, a chart.

They'll let you know, your appointment, when the next one is.

I have all my kids' shot records.

- Respondents offered their own record keeping practices to others to help them to be better keepers of their immunization records.

I have a drawer where I have files like for bills and I keep my shot records there. So I suggest they keep like some kind of file drawer, organizer.

Some people keep them in baby books, too.

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the idea of a registry

- The initial reaction to the registry was both favorable and skeptical. Respondents liked the idea that the registry made immunization records accessible. There was an inherent convenience recognized in the fact that they could find the records in a single location.

The access. It keeps it accessible to all the people that really need it.

It has a single list aspect of it. Going to different health care providers, search for the shot records from each individual one if you have kids in school whatever.

It makes it easy to transfer if you move. You don't have to go jogging all over whatever.

It's keeping up with the 90's, it's modern technology.

- While technology was seen as a plus, it was also seen as a minus because of the potential for errors and issues related to Y2K. The potential for mix-ups was another

concern. The cost and logistics of implementing the registry were also questions raised.

Mix ups, same names.

The year 2000 coming, millennium time, is it going to crash or are they going to take safeguards for that?

Is this the only place it's going to be or is it going to be somewhere else where somebody manually can see it or are we going to just cut the paper trail all together?

Will it actually work? Some parents may not be organized and it may not work for them.

The main question is I would need to make sure that my privacy was still kept you know regardless of whether it's accessible or not.

You still, to a certain point, just want it to be between you and the doctor or whoever is making the transfer. The confidentiality thing, is that going to be kept?

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- There were pros and cons associated with the information indicated for the registry. Specific complaints were tied to the absence of a reference to the father. This is particularly important to this segment because one of the prevailing stereotypes of African American families is that the male is not present.

Why isn't the father's name on there?

- Generally respondents were comfortable with any information related to the vaccine.

The company that made the vaccine.

Type of vaccine.

- Having knowledge about the lot number was important. This was attributed to respondents' references to the bad batch.

I think it's a good idea to have the lot number because of the bad batch and you know all the kids that were immunized with that batch and they can be re-immunized with the right batch, I think that's good.

- Suggested pieces of additional information included the name of the doctor and his telephone number. Respondents thought that the doctor should be contacted in the event of a problem.
- Advantages

It could be an advantage. I don't have a shot record so I can call the registry and have them send it to me. I just moved here from Washington so therefore the information hasn't come across the water so I can just call the registry and say send it to me or send it to that registry or whatever.

The part I like is they can produce a copy of the child's immunization history for school or entering day care because shot records get lost, you know you lose them around the house and if they could produce a copy you know quickly, like that day to give to my day care that day because it's really hard to get a copy of your child's immunization record.

You have to go and sign papers for this doctor's office if you're changing and all that, so it's kind of good they can just call.

B. Reactions to including home address and phone numbers

- Respondents had a level of discomfort with the inclusion of the name and address. Some of this discomfort was attributed to the potential for misuse of the information. It also included issues related to usefulness given the mobility of the population.

The day and age we're living in now, people sell your address to other companies and call you up and hassle you and junk mail. It's easy to sell somebody's address, so I wouldn't be comfortable with that at all.

People move every day.

C Reactions to including parent or child social security number

- Prior to mentioning the social security number as a possible piece of required information, it was brought up as a way to uniquely identify a person.

I think maybe it should be listed under like a Social Security number or something like that, something that you have of your very own because that way you know there's not going to be any mix up.

- When asked specifically about including the social security number there was opposition. The primary reason for that was the potential for fraud.

I don't like to give mine out either.

A lot of people tend to use kids' Social Security numbers. Messing up a kid even before they get started.

C. Reactions to including health care members enrollment (WIC, Medicare numbers)

- Respondents rejected the inclusion of information related to WIC or Medicaid because they were opposed to having information that could be used to single people out.

The norm again is to have everything the same.

III. Access

A. Who should have access

- Respondents in this group seemed a little less restrictive about who should have access, though they expressed issues related to confidentiality and access. Though they included those who might be involved with the immunization from a medical perspective, some also included the pharmaceutical company.
- Doctors
- Some of the people in the clinic.
- Pharmaceutical company

I think the company that made the immunization product and the record company who holds the information while the child is born, gender, sex, maiden name, all that information should be with the company.

- Parents

Parents need access to that too because you can't even get access to your own medical records now.

- The hospital

B. Who should not have access

Respondents seemed to try to exclude those who would profit from having the information or harm those whose information they had accessed. This list included:

- Employers

- For profit businesses like telemarketing
- Creditors
- Insurance companies
- Public health researchers
- Schools

B. *Reactions to ideas of linking registry by computer to other health information systems*

- Respondents were not completely in agreement on the value of linking. They agreed with the concept of health systems being linked but expected any links to fit that criteria and be subject to the same rules for access.

You can get shots at WIC so I think that's a good thing. If it has something medical, something health, then it's a good thing.

IV. Consent and inclusion

A. *Reactions to "opting out"*

- Respondents reacted unfavorably to this alternative primarily because they foresaw a breakdown in the communications path. Most cited misplaced, late or ignored mail as key issues with this alternative. If any of those issues occurred then they would actually have no choice.

Because I might not get it. I mean mail? Is it a registered piece of mail?

Everybody would be included cause nobody would send the letter back.

They think it would be junk mail and nobody would send it back.

- Those who were not familiar with other opting out scenarios questioned the validity of this concept.

Who in their right mind is going to send out something just telling you if you don't respond we're going to do it anyway?

- The key disadvantage of this alternative was that if one missed the notification or delayed in responding, someone else gets to make the decision. The right to choose seemed almost more important than the anything related to the registry.

Everybody should have their choice.

B. Reactions to “consent” option

- This alternative did generate a favorable response primarily because it put the choice in the hands of the respondents. None of the issues related to being notified or missing an opportunity surfaced, they key was having a choice.

The choice is there.

C Reactions to “automatic” option

- This alternative generated a mixed reaction. Though it clearly removed the choice, it removed it for everyone. Respondents still clearly wanted a choice, but were able to recognize advantages to the registry which could possibly offset the loss of choice.

I wouldn't want my choice to be taken away. You're invading my rights. I want to be able to say yea or nay, would it be by letter, phone, by doctor, by whoever, I want to say yea or nay.

I would still want a choice. I would still want my choice but there are advantages to having it automatic.

- A clear negative beyond the having no choice was the issue of how far beyond the immunization registry they could go without consent.

Like if they don't need your consent, they can get it and build it up anyway, perhaps who knows what it builds up to.

- It should be noted that the issue of consent for this group was bigger than the issue of the immunization registry. Respondents tied consent and having a right to choose to issues like voting and the things that African Americans have gone through to get to the point of being heard.

I'd like to say something. With the issue of consent, it gives you the right to say yes or no, so that for me is very important, that consent, yea or nay.

Cause you're saying so. We have say so. It's like voting. I'm able to put my two cents worth in.

It's like voting I guess, for President, and if you've already elected the President and I haven't voted, you know you've just told me --- so it didn't make a difference what I said.

They fought long and hard for me to have an option to say one thing or another, give my two cents about whatever it might be and if I don't utilize that you know one way or another, then I mean what am I doing? I'm putting nothing in. Do whatever, that's the automatic, do whatever.

SECTION 3: ATTITUDES AND PERCEPTIONS OF REGISTRIES

I. Most important benefits of registries

- Respondents cited the key benefits as access, convenience and the reassurance that a back up to their own records existed. Those in the group who were highly involved record keepers seemed to assign the benefits more to those unlike themselves.

II. Greatest concern(s)/biggest risk (s)

- The risks associated with the registry surfaced throughout the session. Respondents cited issues related to access, not only to the information but also questioned whether everyone (African Americans) would be included. Including everyone, particularly immigrants, was not necessarily viewed positively. Some linked the registry to an INS plan to identify which children were born in the US.

So then you just give up all the information and when it comes down to the employer he can say well I see he was treated for AIDS, we can't hire you.

I mean is it going to be in the hood or is it going to be up you know ...? Is it going to reach our neighborhoods or is it going to stay for the rich, the middle class or what? Are we as poor people, are we going to even have access to this? Is this going to reach my community?

That's why they want to do this registry because then it can verify also whether this child was born here or not. I think the reason why all of this is coming up anyway is because they want to know who is and who ain't legal in the United States because now you got a lot of people who come over ...

- Female respondents raised the issue of the danger of having some information available as an easy way for an estranged mate or non-custodial parent to locate those who to that point may have been in a safe and unknown location.

It's sad. He could get her address I mean blow her head off or get his address and blow his head off.

III. Influence of health care provider in decision to participate in a registry

- The group had mixed opinions on whether the doctor's opinion could influence their decision to participate in the registry. Generally, respondents said they trusted their doctor. Others, who seemed to be in managed care with multiple doctors did not always have the same level of trust.

We trust our doctors.

I question mine.

They're giving our children shots, they're looking at our children. We trust them to say our children are healthy or he's got pneumonia or whatever.

If he has my best interests and my child's best interest.

IV. Suggestions/comments to people who are responsible for how system works

- Respondents suggested that attention be paid to the quality of the personnel putting the information in the registry. Errors in the registry could have serious effects so respondents want highly trained individuals putting in the data.

And you don't want them working for \$4 an hour putting that on, not that labor pool that's for sure.